



Invited paper

HIV/AIDS Programming in the United States: Considerations Affecting Transgender Women and Girls

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ABSTRACT

To be truly gender responsive, HIV/AIDS programming for women and girls also needs to be fully gender inclusive. Gender identity is not necessarily determined by one's sex assigned at birth and not everyone is only or always simply "male" or "female." Transgender women (transwomen) and girls are those individuals whose gender identity and/or expression do not align with the "male" sex they were assigned at birth. This definition is inclusive of a diverse population whose identities, language, communities, and behaviors may vary widely. However, based on recent increases in public health literature that aims to elucidate the social context that puts transwomen and girls at risk for adverse health outcomes, we offer some formative considerations for the implementation of gender-responsive and gender-inclusive HIV/AIDS programming in the United States.

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To be truly gender responsive, HIV/AIDS programming for women and girls also needs to be fully gender inclusive. Gender identity is not necessarily determined by one's sex assigned at birth and not everyone is only or always simply "male" or "female" (Greenberg, 2006; Sausa, 2005; Vade, 2005). Transgender women (transwomen) and girls are those individuals whose gender identity and/or expression do not align with the "male" sex they were assigned at birth. This definition is inclusive of a diverse population whose identities, language, communities, and behaviors may vary widely. However, based on recent increases in public health literature that aims to elucidate the social context that puts transwomen and girls at risk for adverse health outcomes, we can offer some formative considerations for the implementation of gender-responsive and gender-inclusive HIV/AIDS programming in the United States.

HIV Rates, Testing, and Prevention

Largely because of pervasive transphobia and the association of negative health outcomes with stigma and discrimination, transgender women experience severe health disparities (Clements-Nolle, Marx, Guzman, & Katz, 2001; Diaz, Ayala, & Bein, 2004; National Coalition for LGBT Health, 2004). Despite the lack of gender-inclusive data collection on a federal level in the United States, regional epidemiological studies have made it alarmingly clear that transwomen and girls are disproportionately affected by HIV, especially transgender women of color. Estimates from urban centers across the United States suggest that HIV prevalence rates among transgender women are among the highest of all risk groups, especially among transgender women of color, and among African-American transgender women in particular (Clements-Nolle et al., 2001; Herbst et al., 2008). Regional reports include 35% in San Francisco (Clements-Nolle et al., 2001), 32% in Washington, DC (Xavier, Bobbin, Singer, & Budd, 2005), 27% in Houston (Risser et al., 2005), 22% among ethnic minority transfemale youth in Chicago (Garafalo, Deleon, Osmer, Doll, & Harper, 2006), and 68% among transgender female sex workers in Atlanta (Elifson et al., 1993). A recent meta-analysis of 29 studies found that in the

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studies that tested participants, 28% of transwomen and girls tested positive for HIV (Herbst et al., 2008). However, in the studies that relied on self-report only, 12% of transwomen reported living with HIV. The high rate of transwomen who are undiagnosed or unaware that they are infected is more than twice the national average (57% vs. 27%; Centers for Disease Control and Prevention, 2008; Herbst et al., 2008). Despite high rates of HIV, multiple barriers to HIV testing exist for transwomen and girls, including lack of knowledge, comfort, and skills among health and social service providers, lack of transgender-friendly testing sites, and a lack of transgender-specific prevention programs that educate transwomen and girls about their risk and the importance of HIV testing (Clements, Wilkinson, Kitano & Marx, 2001; Hussey, 2006; Grossman & D'Augelli, 2006; Nemoto, Sausa, Operario, & Keatley, 2006; Shaffer, 2005).

In addition, public health intervention research has produced no culturally specific, evidence-based HIV prevention interventions for transwomen and girls. Of the few published interventions that have been implemented with transwomen, none have been controlled trials or were rigorously evaluated for effectiveness. The U.S. Centers for Disease Control and Prevention has funded programs to adapt evidence-based interventions for transwomen, but these interventions were developed with other target populations in mind and do not account for the unique cultural context of risk behaviors among transwomen. Given the complex sexual risk factors present among transwomen, HIV prevention programs developed for other populations that are simply adapted to include new language will not ultimately address the cultural context in which risk behaviors occur and in which protective factors develop. HIV prevention interventions need to be based on the culture and context that most influence the lives of transwomen (Sevelius, Grinstead, Hart, & Schwarcz, 2009).

HIV Care and Treatment

Despite high prevalence rates, there has been very little systematic investigation into issues related to HIV treatment and adherence for transwomen living with HIV. The one large quantitative study to date that included transwomen as a comparison group demonstrated that transwomen living with HIV were less likely to be receiving antiretroviral therapy (ART) than other groups (Melendez et al., 2005). In addition, HIV-positive transwomen who were receiving ART were less likely to report optimal adherence than non-transgender people and reported less confidence in their abilities to integrate treatment regimens into their daily lives (Sevelius, Carrico, & Johnson, 2010). When transwomen were compared with other respondents, regardless of the current medication regimen, they reported significantly fewer positive interactions with their health care providers.

Transwomen living with HIV are likely to face culturally unique challenges in adhering to HIV care and treatment regimens, such as limited access to and avoidance of health care due to stigma and past negative experiences with providers, prioritization of gender-related health care, and concerns about adverse interactions between antiretroviral medications and hormone therapy. Anecdotally, health care providers who serve transwomen report that hormone treatment can sometimes serve as an incentive for transgender female patients to seek and adhere to ART, and some providers suggest that integration of hormone treatment into HIV care may augment adherence as

well as decrease the prevalence of self-administered hormone use among transwomen living with HIV (Tom Waddell Health Center, 2006). Understanding patterns of HIV health care utilization, including treatment refusal, ambivalence, and/or low adherence rates among transwomen living with HIV, may lead to different strategies to help transwomen living with HIV make more informed treatment decisions and to improve health outcomes.

Transphobia: Discrimination and Gender-Based Violence

The severe stigma, discrimination, and violence (“transphobia”) that transwomen face underlie many of the HIV-related risk behaviors frequently reported in this population (Lombardi, Wilchins, Priesing, & Malouf, 2001; Sausa, Keatley, & Operario, 2007; Sugano, Nemoto, & Operario, 2006). Experiences of discrimination and victimization negatively impact mental health by increasing anxiety, depression, and suicidality (Clements-Nolle, Marx, & Katz, 2006; Diaz, Ayala, Bein, Henne, & Marin, 2001; DiPlacido, 1998; Hershberger, Pilkington, & D'Augelli, 1997; Johnson, Carrico, Chesney, & Morin, 2008). Experiences of transphobic discrimination and victimization, and lack of social support have been found to be independently associated with attempted suicide, dropping out of school, substance use, and unprotected sex among transgender youth (Clements-Nolle et al., 2006; Lombardi et al., 2001; Sugano et al., 2006). In one Internet sample of 90 transwomen and transmen, African-American transgender women reported the highest levels of transphobic violence, and lower income was correlated with higher reports of lifetime discrimination and perceived stress from transphobia (Lombardi, 2009), emphasizing the interconnectedness of racism, transphobia, poverty, and violence.

Transwomen and girls face pervasive transphobia and transphobic violence from their family, partners, strangers, institutions, colleagues, teachers, and peers (Factor & Rothblum, 2008; Kenagy, 2005b; Lombardi, 2009; Lombardi et al., 2001). However, gender-based violence prevention programs for women are often not inclusive of transgender women. Transwomen and youth seeking shelter from violence are often turned away from women's shelters or forced to deal with harassment and further victimization in the same place they are attempting to seek safety (Mottet & Ohle, 2003). To effectively serve transwomen and girls, shelters need to respect their self-identified gender and communicate that respect through language and policies that address their unique needs (Mottet & Ohle, 2003).

Substance Use

Transwomen often report using substances to cope with the stress of sex work and other stresses associated with the stigma of being transgender (Hughes & Eliason, 2002; Nemoto, Operario, Keatley, & Villegas, 2004; Sausa et al., 2007). Substance abuse has been consistently linked to unprotected sex and HIV status among transgender people (Bockting, Robinson, & Rosser, 1998; Nemoto, Operario, Keatley, & Villegas, 2004). Among transwomen, unprotected sex under the influence of substances seems to be especially prevalent with primary partners (Nemoto, Operario, Keatley, Han, & Soma, 2004; Risser et al., 2005), but is also reported with paying and casual partners (Melendez & Pinto, 2007; Sausa et al., 2007). In San Francisco, transgender people who reported injection drug use were almost three times more likely to be HIV positive (Clements-Nolle et al., 2001). In

Washington, DC, transgender people with high rates of substance use were more than twice as likely to be living with HIV or AIDS than those who did not report abusing substances (Xavier et al., 2005).

Despite high rates of reported drug use and associated negative health outcomes, there are very few recovery or detoxification programs that are safe for transwomen to access and designed to address trans-specific treatment needs (Lombardi, 2008). Few training programs prepare substance abuse treatment providers by imparting the necessary knowledge and skills to support transgender people in treatment. Often, when trans people seek substance use treatment, they are forced to choose between expression of their gender identity or staying in treatment, disclosing or forgoing the use of hormones, and tolerating or combating gender-based harassment from staff and/or other residents (Lombardi, 2008). If trans people are able to find a treatment program willing to serve them, often they are housed according to birth sex and not according to their gender identity and expression. As a result of these negative experiences, many trans people avoid treatment settings altogether. Anti-discrimination policies in drug treatment settings, arranging appropriate accommodations, increasing the sensitivity of providers, and honoring the experiences, preferences, and self-expression of trans people in treatment are all important ways to begin creating trans-inclusive substance abuse treatment programs (Lombardi & van Servellen, 2000).

Incarceration

Rejection from families of origin, being homeless or marginally housed, and unemployment are some primary reasons why transwomen may engage in survival crimes, such as sex work (Sylvia Rivera Law Project, 2007). Sex work may lead to incarceration (Garafalo et al., 2006), which partially accounts for the overrepresentation of transwomen in prisons and jails (Clements-Nolle et al., 2001; Sylvia Rivera Law Project, 2007). When released from custody, transwomen still face employment and housing discrimination and often become caught in cycles of sex work, drug use to cope with sex work, and incarceration (Sausa et al., 2007; Sylvia Rivera Law Project, 2007).

Like shelters, most prisons and jails in the United States sex-segregate prisoners according to genitalia and many transwomen do not have access to genital surgery (even if they would choose it) because of the extremely high costs of these procedures. For this reason, transwomen are usually housed with male inmates, which can lead to violence, sexual assault, and harassment while incarcerated, directly increasing their HIV risk (Scheel & Eustace, 2002; Sylvia Rivera Law Project, 2007). In addition to experiencing violence from inmates and correctional officers, transwomen often do not receive trans competent health care while incarcerated and trans inmates are often denied medically necessary hormone replacement therapy (Scheel & Eustace, 2002; Sevelius, 2009; Sylvia Rivera Law Project, 2007).

Internalized Transphobia and Mental Health

Internalized transphobia occurs when trans people incorporate society's negative beliefs about being transgender into their own self-concept. Internalized transphobia may lead to low self-esteem and high levels of depression and anxiety (Bockting et al., 1998; Melendez & Pinto, 2007). Low self-esteem in turn can lead to unprotected sex. In a Minneapolis study ($n = 175$) of mostly

White transmen and transwomen with high education levels, low HIV prevalence, and low prevalence of sex work, 61% reported depression and 52% reported that they had attempted or considered suicide in the past 3 years (Bockting, Robinson, Forberg, & Scheltema, 2005). Similarly, in a San Francisco study of 392 transwomen, about two thirds (62%) were depressed and one third (32%) had attempted suicide (Clements-Nolle et al., 2001).

Internalized transphobia may also drive transwomen and girls to seek gender affirmation from other people. Transwomen report having unsafe sex to affirm their female gender identities, thereby decreasing sexual negotiation and communication (Bockting et al., 1998; Nemoto, Operario, Keatley, & Villegas, 2004). A new model that conceptualizes how the need for gender affirmation contributes to risk behavior may inform future research and interventions to address sexual risk due to the need for gender affirmation among transwomen and girls.

Sex Work

As stated, experiences of employment and housing discrimination are common among transwomen (Clements-Nolle et al., 2006; Lombardi et al., 2001) and these experiences lead directly to the need to engage in survival sex work for many who are denied opportunities for education, job training, and basic social services because of their transgender status (Clements et al., 1999; Kammerer, Mason, Connors, & Durkee, 2001; Kenagy, 2005a; Sausa et al., 2007). Whether perceived as a choice or a means of survival, sex work is often the norm among transwomen who report rates of involvement as high as 80% (Clements-Nolle et al., 2001) and older transwomen sometimes provide mentorship and guidance in initiating younger women into the practice (Sausa et al., 2007). In fact, sex work has been described as a rite of passage for young transwomen early in their transition (Bockting et al., 1998; Sausa et al., 2007). For young transwomen who are often rejected by their families of origin, acceptance into a community of other transwomen engaged in sex work can provide a much-needed sense of community and social support. In these communities of transfemale sex workers, young transwomen find understanding and acceptance of their transgender identity as well as financial and emotional support from both their colleagues and their clients (Kammerer et al., 2001; Sausa et al., 2007). Although some transwomen and girls do freely choose to pursue sex work in lieu of other types of work, some may come to see sex work as their only means of survival, owing to the lack of other forms of social support, pervasive employment discrimination, and issues with legal documentation of their gender identity (Bockting et al., 1998; Clements-Nolle et al., 2001; Nemoto, Operario, Keatley, & Villegas, 2004; Sausa et al., 2007; Xavier & Bradford, 2005).

In addition to fulfilling basic survival needs, the financial incentive to engage in sex work is especially high for transwomen who pursue gender confirmation procedures, such as taking hormones and undergoing surgeries (such as facial feminization, breast augmentation, and genital reconstruction), which are expensive and usually not covered by health insurance (Bockting et al., 1998; Nemoto, Luke, Mamo, Ching, & Patria, 1999). The financial need created by expensive gender confirmation procedures may lead some transwomen to engage in particularly risky behaviors because sex work clients will sometimes pay more for barrier-free sex or to have the women inject drugs with them (Boles & Elifson, 1995; Nemoto et al., 1999; Nemoto, Operario, Keatley, & Villegas, 2004). Indeed, it

has been demonstrated that transgender female sex workers have higher rates of HIV than non-transgender male or female sex workers (Clements-Nolle et al., 2001; Elifson et al., 1993; Reback, Simon, Bemis, & Gatson, 2001). A recent meta-analysis of studies examining HIV status of transgender female sex workers found that 28% were HIV-positive (Operario, Soma, & Underhill, 2008).

Data Collection Issues and Recommendations

Accurate data collection is essential for dissemination of reliable public health information and development of meaningful gender-inclusive HIV prevention programs and care services. At present, the way in which we collect and report data related to sex and gender is incomplete and results in discrimination against people who do not fit conveniently into binary systems of gender classification. Due to false assumptions and/or lack of knowledge about the importance of accurate data collection and reporting, transwomen and girls are usually either deleted from datasets or miscounted as men who have sex with men (Bauer et al., 2009). In addition, many funders, health departments, and government agencies do not currently allow reports of trans people as clients and patients, effectively erasing their existence from a public health perspective. When collecting data about sex and gender, most agencies permit only one response chosen from two possibilities: “Male” and “Female.” Many providers do not even ask the client or patient and simply complete this information based on their own assumptions. In some cases, agencies may provide one or two additional options: Often simply “Transgender” or “Male-to-Female” and “Female-to-Male.” Today we know this method is too simplistic and binary to accurately and effectively collect this critical information from such a diverse population. If only “Transgender” is provided as an option, it does not tell us enough about the person’s gender to be helpful. In addition, some trans people do not currently identify as “transgender” for a variety of reasons. Some believe it is part of their past experience and is not reflective of their present identity; they may simply identify as “male” or “female,” even though this identity differs from the sex they were assigned at birth. Others may not identify with the word “transgender” owing to cultural beliefs, social networks, and/or linguistic norms in diverse geographic locations.

The Center of Excellence for Transgender Health recommends asking two questions to capture a person’s gender—“What is your current gender identity?” and “What sex were you assigned at birth?”—to both validate a person’s present gender identity as well as understand their history (Center of Excellence for Transgender HIV Prevention, 2009). This method is currently being used at the San Francisco Department of Public Health and in various aspects of the U.S. Centers for Disease Control and Prevention research, training, and evaluation projects.

Conclusion

HIV/AIDS programming for women and girls in the United States must also consider the unique needs faced by those who do not fit neatly into assumptions about fixed and binary genders. We know from regional reports that transwomen and girls are experiencing extremely disproportionate rates of HIV, but are not benefitting equally from the programming, treatment options, and support that are developed without their needs in mind. We need more information about how to make testing and prevention more accessible to trans people, how to support

transwomen and girls living with HIV in their engagement in HIV treatment and care, and how to address and eliminate transphobia and stigma in our health care systems. Issues related to engagement in sex work, experiences with victimization and incarceration, and access to substance abuse treatment and mental health care also need to be considered in the context of HIV/AIDS programming.

To accurately assess HIV incidence and prevalence, identify emerging trends, allocate resources, improve HIV/AIDS programming, and address service gaps faced by women and girls, we need to start with truly inclusive data. With accurate data we can more effectively increase our awareness and understanding of the services needed to address the unique needs of transwomen and girls in the United States, and strategies for improving HIV/AIDS programming for women and girls can more authentically aim to include all women and girls in that important vision.

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